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## QUALITY OF CARE AND QUALITY OF LIFE FROM THE PERSPECTIVE OF PATIENTS AND PARENTS

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### ABSTRACT

Although easily used the concept of *quality* is rather complex, ambiguous, and difficult to measure. Consequently, this applies to the concepts of '*quality of care*' and '*quality of life*', being constructs which as such are difficult to determine and to measure. Although it is supposed that the first contributes to the second, they are often considered as 'opponents' rather than 'friends'. '*Quality of care*' refers to the process as well as to the results of care related to specific goals for a specific type of care as judged by the groups involved. Daily functioning and the appraisal of someone's health or well-being are integral parts of the '*quality of life*'. An often neglected standpoint concerning quality of care is that of the group of pat-

ients, their parents or partners which contributes to the opposing characteristics of both concepts. In case of a chronic condition, they will make use of professional help and care for a long period of time, affecting their quality of life. Therefore, insight into their standpoint concerning the quality of the care delivered to them is urgently needed.

In this article both concepts and their possible relationship will be discussed and illustrated with some examples derived from a research among adult patients with epilepsy, all members of the Dutch Patient Organization and from two researches among parents of a child with epilepsy. From these studies it appears that a) the quality of care provided is often judged as unsatisfactory, that b) the quality of care as experienced by parents may help them in handling their child with epilepsy, and finally, that c) it influences the behaviour of the child via parental child rearing practices. It may be concluded that in this sense, the quality of care provided is not always as optimal as it should be and that it affects the quality of life of parents and child.

**Keywords:** epilepsy; quality of care; quality of life; child rearing; behavioural limitations.

**Running head:** Quality of Care and Quality of Life

## QUALITY OF CARE AND QUALITY OF LIFE FROM THE PERSPECTIVE OF PATIENTS AND PARENTS

### INTRODUCTION

In former days the label '*quality*' was primarily reserved for the production and selling of, for example, automobiles, radios, tv's and other consumer goods. In this context, '*quality*' refers to the concordance between goal and result, i.e. the degree to which the product meets the goal for which it has been produced. From the production process, then, it is required that the material and immaterial costs to produce the good are as low as possible (Harteloh, Casparie & Touw 1991; Klazinga & Casparie 1990).

During the last two decades the label is more and more used in relation to the '*quality of life*' of individuals in the context of current life experiences or across a specific time period. Concerning life experiences, health-related events such as disease or disability, are major life events. Often, the term '*quality of life*' is used as opposed to '*quantity of life*' (Mukherjee 1989). New medical technologies have contributed to a prolonged life span. But it has increasingly been questioned whether this extension of the duration or quantity of life is accompanied by the maintenance of an acceptable level of the quality of life of the individuals involved (Krol, Sanderman & Suurmeijer 1993; Rosendaal, Smit, Varekamp, Bröcker-Vriends, Van Dijck, Suurmeijer, Vandenbroucke & Briet 1990).

Related to the 'quality of life' issue, the '*quality of care*' is emphasized. This attention is strongly associated with the development of new medical technologies mentioned before, but also with several other general societal developments, like the increase of the number of patients with chronic conditions, the ageing of the population in western societies, the emancipation and proto-professionalization of patients, their parents and partners (De Swaan 1990; Mootz 1991), and the medicalization of society (Fahrenfort 1991; Mulder & Tijnstra 1991).

As a consequence, the costs for health care have risen very much, urging national governments to re-allocate scarce financial means with the maintenance of an adequate quality of care. In this context, 'quality of care' became a more important 'matter of concern' for persons, organizations and governments than it was before. Nowadays, it is an important issue for professional organizations, patient organizations and public authorities (Suurmeijer 1992).

Concerning quality of care, as a principle it is claimed that 'the interest of the patient' should take priority. However, it appears that the operationalization of this principle is mostly done from the standpoint of others with neglecting of that of the patients themselves. 'Quality of care' was and often still is considered as the exclusive domain of the care providers, especially of the doctors (Groen, Willemse & Rijkschroeff 1990). But gradually, this is changing as manifested by a growing interest of public policy in 'quality of life' and 'quality of care' issues. Several European Governments including the Dutch Government, are now on their way to develop a health policy directed at an improvement of the quality of care and related quality of life aspects of patients and their families. Of course, within certain financial limits. The importance of the standpoint of the 'consumers of health goods' (patients, parents and partners) is stressed (Council for Health Research 1990, 1991; Ministry of Welfare, Health and Cultural Affairs 1991).

#### WHAT IS QUALITY OF CARE AND HOW CAN IT BE ASSESSED?

Quality of care is not a simple or simply measurable concept. As a 'social construct' it can only be measured via inferences. Elaborating on the former given description of 'quality' as the concordance between goals and results, the Council for Health Research in The Netherlands (1990) defined *quality* as follows: 'quality is the degree in which a set of characteristics of a product, process or service meets the requirements that result from the utilization goal'.

This means that when the quality of care is evaluated, one focuses is at the functioning and the results of a certain type of care in relation to a set of goals which have been formulated for that specific type of care. Care is here conceived as 'all those activities that are directed at people with somatic and/or psychic conditions' and can be 'practised' and studied at the micro-level

(e.g. the care provided to individual patients), at the meso-level (e.g. the structures and organizations delivering care), and at the macro-level (e.g. parts or aspects of the local, regional or national health care system).

Concerning the evaluation of the quality of care, efficiency and efficacy are central elements but other aspects are very relevant as well, like the availability, accessibility and reachability of professional services, the continuity and coordination of care, justice and equity, the safety of means, the expertise and adequacy of the professional workers as well as the way in which patients are treated by the professional workers, and the independence, possibilities for self-care and satisfaction of patients (Casparie 1989; Harteloh & Casparie 1991; Harteloh, Casparie & Touw 1991).

The problematic aspect in this and similar definitions of quality of care is situated in the relation between care and goals. Goals of care are not at all unambiguous. They are differently defined by the parties involved dependent on the position they occupy concerning 'care'. In health care, the parties involved are: patients, nurses, doctors, health insurance companies, institutions for in-patient and out-patient care, and the government. It should not be taken for granted that the goals of the care and the means to reach those goals of all these 'health care parties' will coincide. For example, efficiency of the care process may not concur with patient satisfaction; the introduction of new medical knowledge and skills (i.e. new medical technologies) and the demands of patients may not concur with cost efficiency considerations of health insurance companies or public finances; and so on. Doctors, patients, and other health care parties will *differently judge* about the inclusion or exclusion of certain aspects to evaluate the quality of care as well as about the relative contribution of each of these aspects to the quality of care. In this sense, *the* quality of care does not exist; it is a *subject-bound concept*. Newer theoretical and research approaches concerning the concept of 'quality of care' are based on the so called 'Aspect Approach', an approach that takes into account the several, sometimes conflicting, aspects and standpoints of the relevant health care parties (Casparie 1989; Harteloh & Casparie 1991; Harteloh, Casparie & Touw 1991). Conflicts between health care parties should not be considered as being caused by an 'incompatibilité d'humeurs' but by structural factors.

#### STRUCTURE, PROCESS AND OUTCOME

So, quality of care includes more than merely 'responsible acting' of doctors or other professional health personnel. Confining oneself only to their point of view would not do justice to an adequate evaluation of the quality of the care provided, even more, it would hamper the provision of an adequate quality of care.

In the context of quality assurance, the elements and activities of the health care system can be modelled or arranged along three general dimensions. According to Donabedian (1980),

these are: structure, process and outcome. Supposedly, a relationship between these three general dimensions exists and the elements, involved in each dimension, are related in several ways to 'quality of care' (Figure 1).

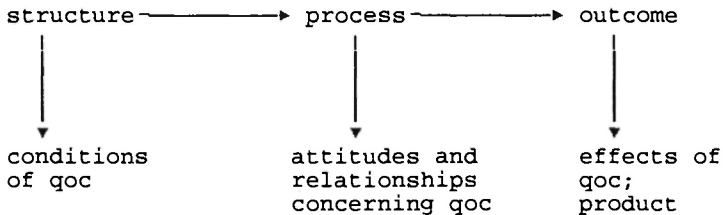


Figure 1. The structure-process-outcome model.

*Structure* refers to the material and immaterial conditions which may influence the provision of care or a certain type of care, e.g. continuity, accessibility or coordination.

*Process* refers mainly to the direct delivery of care in a technical as well as in the sense of: treatment and interactions, attitudes and social skills of professional workers.

*Outcome* or product refers to a change in the actual or prospective 'health situation' of the patient as a result of the health care provided, e.g. morbidity and mortality, but also compliance and patient satisfaction.

Much attention was and is paid to the structure and process aspects especially on the level of nations and organizations. An underlying assumption in this type of research and in health care policy is that when the structure and the process meet the requirements, the outcome will be good (Casparie 1989).

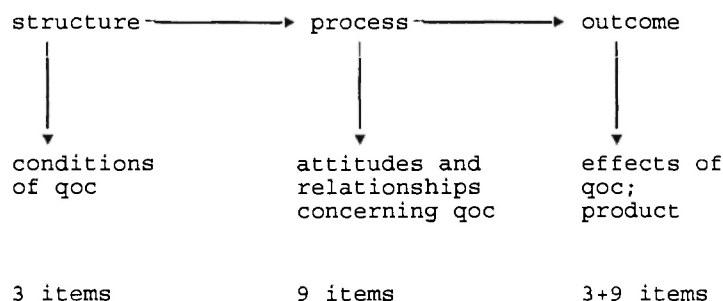
What outcome measures should be taken to measure and evaluate 'quality of care'? In his article on 'outcome measurement: concepts and questions', Lohr (in: Casparie 1989) discussed the 5 D's as outcome parameters: *Death, Disease, Disability, Discomfort, and Dissatisfaction*. Several of these parameters, especially those on an aggregated level like mortality and morbidity statistics, are rather crude and dependent on registration systems while demographic and epidemiological factors also have a great influence on these outcomes (Blaxter 1981; Casparie 1989).

But in the end, it is the *outcome of the care delivered that counts*. Therefore, more and more attention is paid to the *health status* and *patient satisfaction*. And both of them are closely related to the quality of life concept and measurement.

Before going into 'quality of life issues', some data on 'quality of care' of an often neglected

party: the group of (potential) consumers of health care, will be presented. Today, in health policy the standpoint of the patients and significant family members is strongly emphasized. Their experiences should be taken very serious and, more than before, be included in the development and evaluation of an adequate quality of care and in all phases of the quality control process (Ministry of Welfare, Health and Cultural Affairs 1989, 1991; Committee for Rheumatism Research 1990; Council for Health Research 1990). However, because of their relatively dependent and powerless position, their point of view is often neglected or considered as not very important or even as not very credible.

Therefore, the Dutch Epilepsy Patient Organization (Epilepsie Vereniging Nederland - EVN) asked me to carry out a small research among their members. The aim of the study was to highlight some aspects of the quality of the care provided by the medical specialists as experienced by the patients with epilepsy or their parents or partners. To this end, data were collected from 1107 patients, partners or parents by means of a mail questionnaire.



*Figure 2. The structure-process-outcome model and related questions in the questionnaire.*

As is shown in Figure 2, the questions in the questionnaire were directly related to the 'structure-process-outcome' model of Donabedian mentioned before.

The 'structure' or 'condition' items were primarily focussed on the accessibility of the medical specialist. The 'process' items referred to relational and informational aspects of the doctor-patient relationship while the 'outcome' or the 'product' of the care process was measured in terms of satisfaction defined and measured as the difference or discrepancy between what was needed and what was provided.

Using a principal component analysis and an orthogonal rotation according to the varimax criterion, carried out on these items, four factors were extracted measuring the degree to which

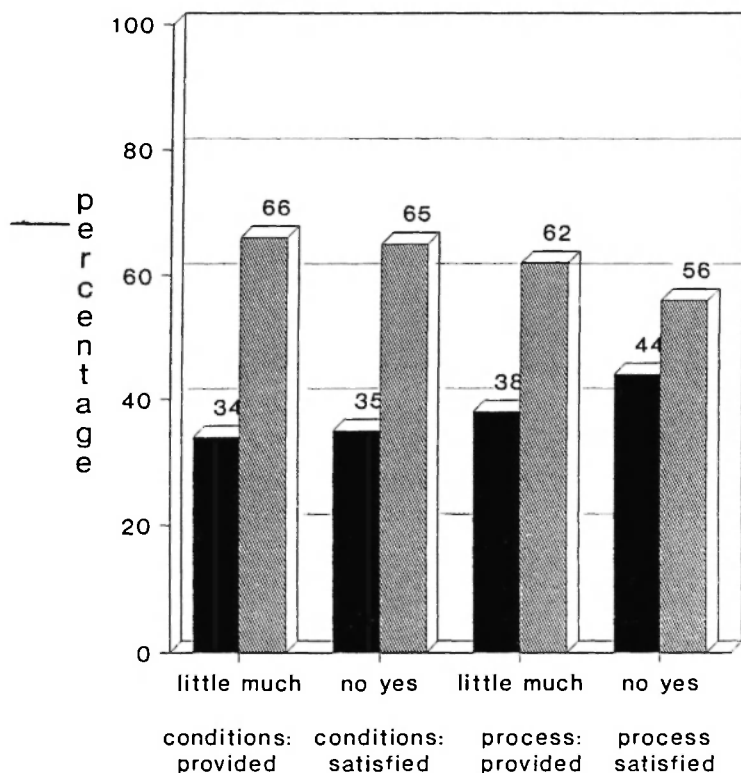


Figure 3. Provision of and satisfaction with care provided

the respondents were provided and satisfied with the 'quality aspects' of care.

As is shown in Figure 3, slightly more than one third (34%-38%) stated that the conditions and process aspects of care distinguished were not provided to them. About the same percentage (35%-44%) said to be dissatisfied with the care provided to them.

Although a quite different way of questioning was used, about the same percentage of satisfied/dissatisfied patients were recently found among a group of patients with multiple sclerosis (Van der Plas et al. 1990).

There were several differences between subgroups within our sample: most notably were the differences by duration of membership, but there were also several differences by gender or age of the respondent. Concerning age it appeared that younger people were, more than older people, interested in information and discussion about effects and side-effects of medication, 'epilepsy and pregnancy', 'epilepsy and education' and 'epilepsy and work'.



From these results it may be concluded that much can be done, and at low costs, about the accessibility, relational and informational aspects, that is: the structure and process of care, to further enhance the quality of care as experienced by the patients.

#### QUALITY OF CARE AND THE QUALITY OF LIFE OF PATIENTS

In the former conclusion, a quality of life perspective is implied. Before, I referred to some parameters (5 D's) to measure the outcome of the care supplied. One of these measures was: health status. A broad conception of health status as is implied in the WHO definition of health, may be put on a par with the concept of 'quality of life'. In this context, a 'health related quality of life' concept is involved, i.e. the quality of life of people as far as it is related to health, illness or medical interventions. Often, the same instruments are used to assess health status as well as quality of life (Bowling 1991; Dictionary of the Rheumatic Diseases 1988). Especially when chronically ill persons are involved, treatment is mostly not so much directed at 'cure' but rather at the utmost prevention of adverse consequences of chronic diseases to optimize their 'normal functioning' ('care'). For that reason, quality of care and (health related) quality of life are very closely connected: studying quality of life issues in order to improve quality of care for people with a chronic condition. But the reverse is true as well: studying quality of care in order to enhance quality of life as much as possible. For a careful evaluation of the consequences of a chronic illness or medical treatment, the use of only clinical data do not suffice (Suurmeijer & Hermann 1992).

Therefore, enhancing the quality of care in terms of patient satisfaction will doubtless affect the quality of life of the persons involved: patients as well as their parents and partners.

A relationship between quality of care and quality of life is also implied in the doctor-patient role model as proposed by Szasz & Hollender (in: Bartlett 1984) (Table 1).

*Table 1. A typology of doctor-patient relationships*

| ROLE RELATIONSHIP       | NATURE OF CARE              |
|-------------------------|-----------------------------|
| 1. Activity/passivity   | Emergency care; anaesthesia |
| 2. Guidance/cooperation | Infectious disease          |
| 3. Mutual participation | Chronic illness; prevention |

Source: Bartlett 1984, p. 19

The third type of role relationship is of particular importance for chronic disorders as, for example, epilepsy. Within this role model the patient becomes more actively engaged in the treatment programme, and attention is paid to the experiences and the experiential knowledge of the patients and of his/her nearest relations involved. This will enhance both the patient's satisfaction with the care provided and the patient's quality of life (Suurmeijer 1988). For in the 'patient satisfaction approach' of quality of care, the conception is implied that this patient satisfaction is determined along with the meaning and consequences that the quality of care received has for the daily functioning and both for the life-domain-specific satisfaction and for the global satisfaction with life from the subjective perspective of the individual. And this is at least one conception or definition of what 'quality of life' is supposed to be (Fabian 1991).

Concerning quality of life, many 'areas of concern' or 'life-domains' have been distinguished; they can be subsumed under the headings of *physical symptoms*, *psychic functioning* and *social functioning* (Krol, Sanderman & Suurmeijer 1993; Spilker 1990). However, most of the literature and the research practice is exclusively patient-based or patient-directed. Community and family aspects are not mentioned (Suurmeijer & Hermann 1992). I will apply this point of view to 'epilepsy' as one of the most frequent chronic conditions occurring among children.

In epilepsy as other in chronic conditions, '...total eradication of the physical symptoms remains the goal of the physicians. Yet, this is not enough, for the family and the community are also involved. The treatment does not end with a diagnosis and a prescription - it really just begins at this point' (Boshes & Kienast 1972). This idea is shared by many others (see e.g. Aldenkamp, Alpherts, Meinardi & Stores 1988; Rodin 1972; Smits 1970; Suurmeijer & Van den Nieuwenhuijzen 1986). It appears that epilepsy will not only have *direct* effects on the quality of life of people with epilepsy but also serious *indirect* effects via the community and the family. There is ample evidence that parental behaviour is often of great influence on the psychic and social functioning of the child with epilepsy. In addition, the quality of life of the parents themselves is influenced by the epilepsy too. That will affect the functioning and hence the quality of life of the child with epilepsy.

To to give an example of this complex interrelationships, I will inspect data derived from two studies among parents of a child with epilepsy. In one study among fathers and mothers of an 11 year old child with epilepsy we asked the parents whether adequate information given to them by their doctor, would help them in adjusting to the epilepsy and the child with epilepsy (Table 2).

Table 2. Information and parental attitudes towards the child with epilepsy\*

|   | (strongly) agree |         |
|---|------------------|---------|
|   | Mothers          | Fathers |
| If you know what is wrong with your child:                                  |                  |         |
| 1. You also will more easily accept that something is wrong with your child | 87%              | 95%     |
| 2. You will be less frightened as well                                      | 60%              | 76%     |
| 3. You also know better how to deal with your child                         | 72%              | 98%     |

\* Source: Suurmeijer and Van den Nieuwenhuijzen 1986, p. 132

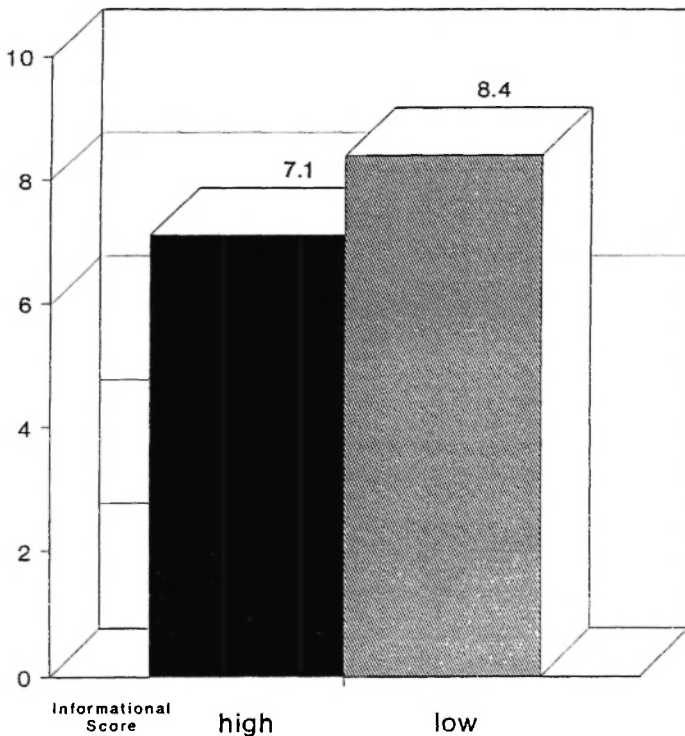
This table shows that when parents are adequately informed by their doctor, this would be a great help to them in adjusting to the child with epilepsy and the epilepsy itself. In my opinion these figures may be interpreted as aspects of both 'quality of care' and 'quality of life'.

In another study among parents of a child with epilepsy of about nine years of age, we asked them, among others, to evaluate the informational behaviour of their doctor using a nine item hierarchical scale measuring 'information' ('information scale'). We also asked them to indicate how many of eighteen behavioural restrictions, they had imposed on their child. These restrictions varied from: reading books, watching TV, swimming, cycling, and so on. Then we calculated the mean number of restrictions imposed on the child and related this to the information provided by their doctor (Suurmeijer & Van den Nieuwenhuijzen 1986).

On average, the parents imposed one or two restrictions less on their child when the information given to them was adequate (as evaluated by the parents) than in case of inadequate informational behaviour of the doctor.

From a *quantitative* point of view, the difference in mean number of restrictions seems not too large. From a more *qualitative* point of view and from the standpoint of the child, however, even one restriction extra may make a great difference for children of this age because it may place them in a special position as compared to their brothers, sisters and peers. And that should be avoided as much as possible as it will impair the mental and social functioning of the child with epilepsy and hence its quality of life.

So, it may be concluded that via the information given by the doctor (which is a 'quality of care



*Figure 4. Information and mean number of behavioural restrictions imposed on the child*

aspect'), the parents will more adequately adjust to their child with epilepsy (which is a 'quality of life aspect' of the parents). Consequently, they impose less behavioural restrictions on their child with epilepsy (which is a 'quality of life aspect' of the child).

#### CONCLUSION

Epilepsy may affect many aspects of life 'beyond the skin' such as education, housing, employment, partner choice, and so on. Therefore, a broad approach of 'quality of life' in both research and medical practice may be appropriate (Hermann 1992; Suurmeijer & Hermann 1992). Concerning many aspects of daily functioning of people with epilepsy, their parents or partners, a 'more active participation' of doctors may be required by that improving the quality of care as well as, directly and indirectly, improving the quality of live of those involved (Suurmeijer 1992).

'Quality of care' and 'quality of life' sometimes appear to be 'opponents'. Instead they should be 'friends' if we take the priority principle serious that the care provided should always be in the interest of the patient.

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